What is Interstitial Cystitis?

Interstitial cystitis (IC) is pelvic pain, pressure, or discomfort related to the bladder typically associated with urinary frequency and urgency, in the absence of infection or other pathology. IC is also called painful bladder syndrome and bladder pain syndrome.

Who is Affected?

IC can affect women, men, and children of any age, race, or sex. Three to 8 million women in the United States may have IC. Somewhere between 1 and 4 million men may have IC. Prevalence among children is unknown; however, many patients report experiencing IC symptoms as children.

Symptoms

Symptoms of IC differ from person to person and may even vary in the same individual. Some or all of these symptoms may be present:

• Frequency: Day and/or night frequency of urination. In early or very mild cases, frequency may be the only symptom.
• Urgency: The sensation of having to urinate immediately, which may also be accompanied by pain, pressure, or spams.
• Pain: Patients may experience painful sex and pain in the lower abdomen, urethra, vagina, and vulva, scrotum and perineum area.

Hunner’s ulcers, also called lesions or patches, are characteristic of “classic” IC, which affects only a minority of people with IC. They are not ulcers in the usual sense but distinctive areas of inflammation on the bladder wall.

IC patients often have certain other health conditions. Allergies, irritable bowel syndrome, pelvic floor dysfunction, vulvodynia, and endometriosis are common. Fibromyalgia, migraine, chronic fatigue syndrome, vulvodynia, and endometriosis are common. Fibromyalgia, migraine, chronic fatigue syndrome, vulvodynia, and endometriosis are common. Fibromyalgia, migraine, chronic fatigue syndrome, vulvodynia, and endometriosis are common. Fibromyalgia, migraine, chronic fatigue syndrome, vulvodynia, and endometriosis are common.

Diagnosis

There is currently no diagnostic test for IC. The diagnosis of IC is based on the presence of pain or pressure in the bladder, urethra, or pelvic area usually accompanied by frequency and urgency and the absence of other diseases that could cause the symptoms.

A urine culture is usually done to rule out infection. Other tests check for other conditions that can cause the symptoms. If the diagnosis is still in doubt or symptoms are complicated, further tests such as cystoscopy or urodynamic studies may be needed.

Treatments

At this time there is no cure for IC. Most patients will need a combination of treatments. Finding the best combination may take trial and error.

IC DIET & SELF CARE

Knowledge and self care are the first step. There are many things you can do on your own to take control of your symptoms and to feel healthier. Many are helped by eliminating bladder irritants from their diet such as carbonated beverages, soda, alcohol, citrus fruit and juices, artificial sweeteners, hot pepper, and tomatoes. However, food sensitivities and intolerances vary widely.

Stress management can also be very useful. Relaxation techniques, meditation, visualization, massage, and psychotherapy can help you reduce stress, ease pain, and cope with IC’s challenges.

To help reduce symptoms, get restful sleep, do low-impact and stretching exercises, use heat or cold over painful areas, and drink enough to dilute your urine but not so much that it increases your frequency.

PHYSICAL THERAPY

Physical therapy to treat underlying pelvic floor dysfunction can yield positive results and provide significant pain relief. Working with a physical therapist who understands IC is the key, because Kegel exercises, often recommended to strengthen pelvic muscles, can worsen pain.

ORAL MEDICINES

The only oral medicine specifically approved by the FDA to treat IC is pentosan polysulfate (Elmiron®). In clinical trials, the drug improved symptoms in 30 percent of patients treated. Doctors do not know exactly how it works, but one theory is that it may repair a thin or damaged bladder lining. Prescription multi-ingredient products (eg, Urelle®, Uribel®) are also available to relieve urinary pain and lessen the urgency/frequency of having to urinate. Over-the-counter (OTC) products such as aspirin, ibuprofen, and urinary tract pain relievers (eg, AZO®) can help to alleviate mild pain.

Other oral medications, though not approved specifically by the FDA for the treatment of IC, have been useful for treating the condition. These include acid-blockers like cimetidine (Tagamet®) and the antihistamine hydroxyzine (eg. Atarax®, Vistaril®). Many IC patients benefit from taking tricyclic antidepressants such as amitriptyline, or antiseizure, or nerve pain drugs. In severe cases, immunosuppressants such as cyclosporine may be effective. All drugs – even those sold over the counter – have side effects. Patients should always consult a doctor before using any drug.

BLADDER INSTILLATIONS

Some people with IC benefit from instillations (bladder cocktails), which are medicines or mixtures of medicines slowly instilled directly into the bladder. They can provide immediate relief of pain and may also reduce inflammation.

NEUROMODULATION

Neuromodulators send mild electrical pulses to nerves. Some are external, others are surgically implanted. Devices that stimulate the sacral nerve roots at the base of the spine may reduce urgency and frequency and, sometimes, pain. Those with devices implanted in the spinal canal itself are used to relieve severe pain.

HYDRODISTENTION AND SURGERY

When self care, physical therapy, and commonly used oral medications don’t control symptoms, stretching the bladder with water for a short time and with low pressure while you are under anesthesia may help. This may increase pain in the short term, so pain control is important.

Major surgery, such as diverting urine from the bladder, removing the bladder completely, or enlarging it, is considered only as a last resort.

BOTOX

While not FDA-approved for IC, botulinum toxin type A (Botox) injections into the bladder are used experimentally to treat IC and other bladder
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Thank you for helping to bring hope to the millions who suffer with IC.  We look forward to welcoming you as a generous supporter of ICA and its vital work.

About the ICA
The Interstitial Cystitis Association (ICA) is the only nonprofit association dedicated solely to improving the quality of healthcare and lives of people living with interstitial cystitis (IC).

Conquering IC. Changing Lives.
The ICA provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC. Our work is made possible through the generosity and vision of our donors.

Donations help us to keep programs and services operating at peak strength so that every IC patient who needs help can have it—no matter where he or she may live, no matter how disabled they may be.

Your donation dollars also enable the ICA to continue to fund new IC research projects as well as to work closely with Congress to ensure ongoing federal funding of IC-specific research.

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